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# When It Hurts to Ask: Avoiding Moral Injury in Requests to Forgo Treatment

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# When It Hurts to Ask: Avoiding Moral Injury in Requests to Forgo Treatment

## **Abstract**

Clinicians commonly believe that "there is no harm in asking" patients with life-threatening illnesses if they would like to forgo aggressive therapy. In fact, many clinicians believe that the question is not only appropriate, but obligatory on grounds of patient empowerment and autonomy: Patients should be given all options, including the option to stop treatment. But in this piece, I argue that there is, indeed, serious -- and even traumatic -- harm in asking patients to forgo treatment if that request is perceived by the patient as evidence that the clinician devalues or questions the integrity of that patient's life. When such requests are perceived to imply: "Your life is not worth saving," the effect of the "ask" is insult and offense, not empowerment. I then argue how clinicians can avoid moral injury in conversations about withholding or withdrawing treatment.

## **Keywords**

bioethics, clinical ethics, medical ethics

## **Disciplines**

Bioethics and Medical Ethics | Medicine and Health Sciences

## **Comments**

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When It Hurts to Ask: Avoiding Moral Injury in Requests to Forgo Treatment

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## When It Hurts to Ask: Avoiding Moral Injury in Requests to Forgo Treatment

### Abstract

Clinicians commonly believe that "there is no harm in asking" patients with life-threatening illnesses if they would like to forgo aggressive therapy. In fact, many clinicians believe that the question is not only appropriate, but obligatory on grounds of patient empowerment and autonomy: Patients should be given all options, including the option to stop treatment. But in this piece, I argue that there is, indeed, serious -- and even traumatic -- harm in asking patients to forgo treatment if that request is perceived by the patient as evidence that the clinician devalues or questions the integrity of that patient's life. When such requests are perceived to imply: "Your life is not worth saving," the effect of the "ask" is insult and offense, not empowerment. I then argue how clinicians can avoid moral injury in conversations about withholding or withdrawing treatment.

## When It Hurts to Ask: Avoiding Moral Injury in Requests to Forgo Treatment

### Case

Mr. Jones is a 55-year-old paraplegic who became paralyzed several decades ago in an accident. He is now suffering from an infected Stage 4 wound and has recently had it debrided. He is facing a long treatment course with poor odds of recovery. His treating physician broaches the subject of palliative care and the withholding of aggressive therapy.

### Comment

In a telling recent testimonial(1), disabled cultural anthropologist William J. Peace describes the experience of being asked to consider forgoing life-sustaining treatment for a seriously infected wound that, while medically treatable, would entail a long, arduous recovery. In his retrospective, Peace relays how his physician reviewed, in excruciating detail, the difficult road he would face to recovery. The clinician then offered Peace the option to simply forgo all life-prolonging measures and choose the alternative of comfort care.

What might have seemed to the physician an obligatory conversation to disclose the full range of treatment options was experienced by Peace as an emotional and ethical injury—one that he terms the “denial of personhood.” Peace writes as someone genuinely traumatized, saying that he is “haunted” by this “unforgettable” conversation; that it “gnaws” at him “to this day;” and that he is still “paralyzed...with fear.” His critique of the physician is a moral one because Peace feels wronged and “discriminated against.” How did a clinical discussion considered commonplace (and even compulsory) have this devastating effect on its recipient and provoke such moral reproach?

In most cases, the ostensible motivation for suggesting the withholding of life-sustaining treatment is to bolster patient empowerment, thereby allowing the patient to make a truly informed decision about the course of treatment. If an appreciation of all options is a

prerequisite for exercising the right to choose among them, such conversations tend to be perceived as a beneficent means of facilitating patient autonomy. Thus, a typical context for raising the issue of withholding life-sustaining therapy would be end-stage illness, when patients might be grateful to know that they have the clinical option to stop aggressive therapy—i.e., the “permission” to put the option of hospice or comfort care on the table. Peace’s physician was clearly tapping into this common rationale, as Peace was empathically told, “The choice to receive antibiotics was mine and mine alone.”

Then what went wrong? The conventional view of conversations about withholding or withdrawing treatment is that they do no harm as long as the patient is not coerced into agreement or assent. The rationale in the adage “There’s no harm in asking” is that the person asked can always say “No.” But this logic naively assumes that the question *itself* carries no moral cost. With coercion identified as the only moral liability in discussions of withholding treatment, Peace’s emotional and moral reactions seem to have no traction: after all, he could and did say “no,” therefore he couldn’t have been coerced. But this analysis of “asking” is too simple: What we inquire of others reveals a great deal about our perceptions, assumptions, and estimations of them—and therein lies the source of Peace’s feelings of distress and offense when asked if he wanted to stop curative therapy.

In order for the physician to raise the specter of comfort care in Peace’s case, he had to believe that death was a legitimate (and arguably preferable) option to living with this illness, this level of prolonged suffering, and this long trajectory to meaningful recovery. The request had embedded in it a judgement that suggests, all things considered, that Peace’s life might not be worth the fight it would take to save it. This makes Peace’s case very different from withholding conversations that take place in the context of end-stage illness. In those cases,

there is no recovery or medically possible cure; and therefore no value judgement that the benefit of survival is outweighed by the costs of securing it. Peace was the recipient of an unfavorable verdict about the worth of his life. He was deemed by the physician as having what we might call a *value-negative life*: an existence that, on balance, entails far more pain and suffering than any amount of good that can come from continuing it. Peace's testimonial supports this interpretation. He writes of the physician's mindset: "Clearly death was preferable to nursing home care, unemployment, bankruptcy, and a life-time in bed."

To be judged by someone as having a *value-negative life* is to be assaulted in two substantially different ways. First, it is an insult to the integrity of that life, tantamount to saying, "Your life isn't worth the price of *your* \_\_\_\_\_ (physical pain, financial expense, emotional suffering, compromised level of activity)." It is the presumptuous assessment of an outsider whose vantage point is inherently blinded to all that makes life good and worthwhile from the insider's view, to the possessor of that life. It is a dismissal of the reasons his life has value for him and for the people who love him. It is this insult that explains Peace's feelings of indignation, resentment, and affront.

But there is a second level of assault in being deemed to have a *value-negative life*; and it explains Peace's fear. Such a calculation carries a menacing threat, namely: "Your life isn't worth *my* \_\_\_\_\_ (trouble, effort, expense, sympathy, anguish)." Asking a patient to forgo life-sustaining therapy in such situations implies that the patient is a bother, a nuisance, a waste of time, or a squandering of clinical resources. Moreover, it raises the specter of an ominous price-tag being placed on one's life and one's continued care. But what follows when one's life isn't valued, when someone's death seems a better alternative to his existence? Third-person estimations of *value-negative lives* have wrought many destructive, even violent, consequences

to their recipients. Fear is the natural response to having to justify one's existence to someone else: one must offer compelling enough reasons to safeguard one's life from those who deem it to have little value.

The burden of having to defend one's life to one's physician is the source of Peace's claim of discrimination: He is being asked to defend his existence when others are not.

Wheelchair-bound for 25 years, Peace argues that the root of such discrimination is a bias against the physically disabled—which he calls “disablism,” borrowing a term from the disability studies literature.<sup>(2)</sup> But being deemed as having a *value-negative life* affects a much broader group of patients, not just the disabled, though he may well be correct that the disabled can categorically claim to be societally de-valued. Patients with chronic, intractable illnesses; those who are bed-bound, comatose, or in unrelenting pain; and patients with severe mental illness or cognitive impairment are equally vulnerable to this same, unfair assessment.

So how can the well-intentioned physician promote the patient empowerment that comes from having medical choices – including forgoing treatment – while avoiding the harm sometimes done by the very suggestion of that choice? Perhaps the criterion for requests to forgo treatment in conscious, competent patients should mirror the one employed for unconscious, incompetent patients: Is the patient's condition terminal? Surrogate decision-makers are only asked to consider withholding or withdrawing life-sustaining treatment when their loved one's illness is end-stage or terminal. The rationale for this criterion is that life-sustaining measures in terminal patients are best understood as death-prolonging, rather than life-enhancing. The surrogate decision-maker is not being asked to render a verdict on the value of the patient's life, but on the quality of the patient's death. Requests to forgo treatment laid bare are really conversations about how best to die. But in non-terminal patients, talk of a “good



death” can easily be viewed – as Peace’s story relays – insulting and threatening at worst. Could a helpful “rule of thumb” be that, with terminally ill patients, physicians can broach the subject of withholding care that should be patient-initiated in the non-terminally ill?

The immediate objection will be that some non-terminally ill patients very much welcome the “permission” to back off on aggressive therapies that may be costing them an inordinate amount of suffering. The argument goes that, if withholding conversations are withheld from the non-terminally ill, those patients who really want to stop but can’t bring themselves to, in the absence of their physician’s support, will not be able to raise the possibility on their own. But this objection can be easily met: non-terminally patients can make a request to withhold aggressive therapy without *literally* requesting it. They can allude to the burden of the therapies, speak about not being able to endure them any longer, express despair or frustration at the prospect of adding new therapies to their regimen. Any of those signs would count as a patient-initiated conversation of withholding – without the emotional liabilities experienced by Peace.

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